Parents’ experience of having a child with the dual-diagnosis of Down’s Syndrome & Autism Spectrum Disorder: A Narrative Analysis

Katie Lambert, Dr Kate Gleeson & Dr Emma Williams, University of Surrey

Summary of the Findings

Background
To date, research undertaken on the dual-diagnosis of Down’s Syndrome and Autism Spectrum Disorder (ASD) has largely focused on exploring the behaviour and features of those with the dual-diagnosis (DS-ASD) and how these characteristics are distinct from what one might expect from a child with Down’s Syndrome without ASD. No research has been undertaken to explore parents’ experience and what it means for them to have a child with Down’s Syndrome who later receives a second diagnosis of ASD. Instead, generalisations and speculations are gained from wider evidence of parents’ experience of having a child with a disability or whose child has a diagnosis of either Down’s Syndrome or ASD, but not both. This exploratory study sought to explore how parents of children with Down’s Syndrome experience and make sense of their child’s additional ASD diagnosis.

The Study
In order to gather accounts that were rich in detail and meaning, in-depth, face-to-face interviews were undertaken with six parents of children with the confirmed dual-diagnosis, recruited from the Down’s Syndrome Association (DSA). Participants were invited to tell their stories about having a child with the dual-diagnosis of Down’s Syndrome and ASD. This included recounting especially significant situations and exploring what meaning and role their child’s dual-diagnosis has in their everyday lives.

The Findings
The findings suggest participants have difficulty making sense of their child’s diagnoses of Down’s Syndrome and ASD and what this means for their identity, sense of belonging and where best to seek support. All the participants described a distinction between a ‘Down’s Syndrome’ identity or group and that of an ‘ASD’ identity, and related this to a sense of not belonging or fitting in. Using terms such as ‘camp’, some participants spoke about having ‘one foot in both camps’, others stated that they do not ‘fit
in either’ or considered themselves on the periphery of a minority group of parents of children with a disability.

To navigate this and seek a sense of belonging and meaning, parents talked about ways they have come to understand, respond and engage with their child’s dual-diagnosis. For example, for some, the routine day-to-day and social impact of their child’s ASD diagnosis is considered greater than that of Down’s Syndrome. Others reflected on the complexity of the dual-diagnosis, precluding the separation of the two conditions, describing DS-ASD as a ‘cocktail’ where the two conditions are mixed together. A level of adjustment and acceptance was implied by some participants in their account of their child’s behaviour and family circumstances becoming ‘the new norm’.

All the participants spoke about ways in which they respond to having a child with DS-ASD, and for some this resulted in their role as a parent developing and expanding. While warmth and affection were evident across the participants’ accounts, a sense of responsibility was expressed. Most of the participants spoke about a ‘need’ to seek knowledge, to ‘get it right’, ‘to pick your battles’, and to be sufficiently organised and prepared in order to manage situations in an effective way for their child. Accessing the most appropriate education for their child was an especially important issue raised by several of the participants.

The diagram below is a tentative visual representation of the findings in order to highlight the extent to which the participants’ experiences and sense-making process is complex, continuous and non-linear.
The findings gathered in this study support previous research which outlines the importance of the search for and integration of meaning in the process of acceptance and adjustment for parents of children with a disability/illness and the extent to which this provides an opportunity for personal growth and a shift in parents’ values.

**Implications**

Sources of support currently in place tend to focus on the indirect, informal sharing of practical ideas between parents and carers. While further research is required to gather a broader range of parental experiences, the current findings provide some evidence to indicate that it may be necessary to consider the provision of support specifically for parents of children with DS-ASD. Given that having a child with the dual-diagnosis involves numerous changes and transitional events, parents are likely to benefit from having an opportunity to share their stories, talk about their experiences and reflect on the complexities and contradictions of having a child with the dual-diagnosis in a space, such a DS-ASD specific, therapeutically-based parent support group where there is mutual awareness and understanding amongst group members.

**Conclusion**

The findings demonstrate the challenging nature and complexity of what it means to parent a child with DS-ASD and how parents come to find meaning from their unfolding understanding of their child. While further research is required to gather a broader range of parental experiences, the findings provide some evidence for support specifically for parents of children with DS-ASD.

**Dissemination of the Findings**

In addition to providing members of the DSA with a summary of the study findings via publications on their website and attendance at the Down’s Syndrome with Complex Needs meetings, it is anticipated that this study will be published in an article for an academic journal so that the findings will be available to others working in this field. Furthermore, the study was represented during a poster-presentation session at the Trisomy 21 Research Society (T21RS) 3rd International Conference in Barcelona in June 2019.

If you have any questions or would like more information about the study, please contact:

**Katie Lambert** (Trainee Clinical Psychologist)

E-mail: k.lambert@surrey.ac.uk

School of Psychology. University of Surrey. Guildford. Surrey. GU2 7XH.

**Dr Kate Gleeson**

E-mail: kate.gleeson@surrey.ac.uk

School of Psychology. University of Surrey. Guildford. Surrey. GU2 7XH.