

‘They obviously think we’re misfits’:

The lived experiences of parents of autistic children with learning difficulties and their perceptions of societal attitudes to autism



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1. Context

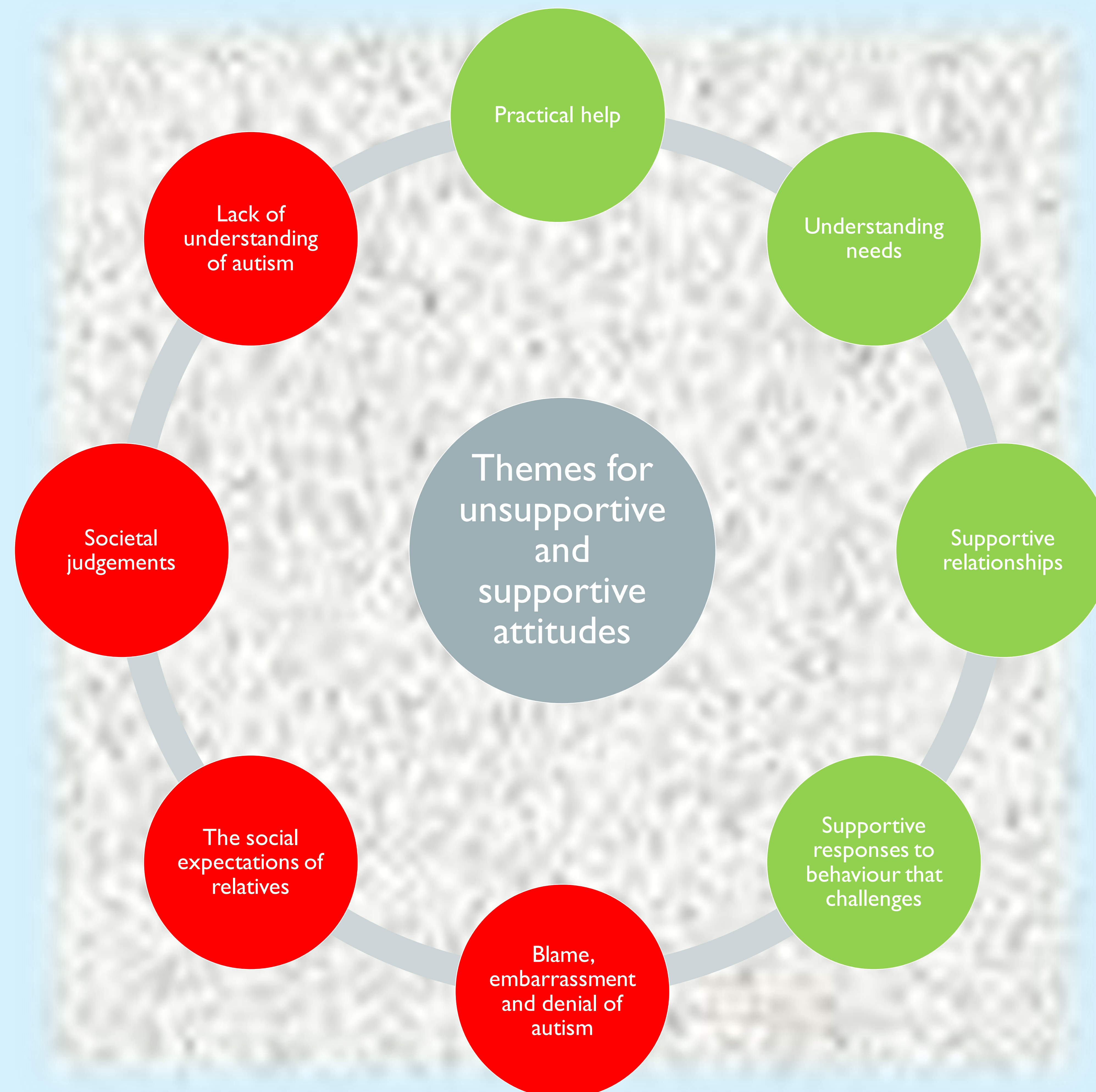
- Little is understood about the experience of parents of autistic children with learning difficulties and other co-occurring conditions
- Little is known about how this group are affected by societal attitudes towards autism

2. Aims

- **Broad focus-** to highlight the forgotten experience of parents of autistic children with learning difficulties
- **Narrower focus-** to explore these parent’s experiences of attitudes towards autism

3. Methodology & Conceptual framework

- Combination of phenomenological methodologies (Narrative inquiry and Interpretative Phenomenological analysis- methods for exploring lived experience)
- Purposive sample of 8 parents of autistic children with learning difficulties and other co-occurring conditions
- 2 Phases of semi-structured interviews
- Conceptual frameworks- Ecological systems theory and Developmental niche
- Researcher positionality central to research design and interpretation of parental experience



4. Findings

- A range of unsupportive and supportive attitudes were perceived across multiple settings
- These judgements were often subtle or hidden
- Unsupportive attitudes were underpinned by lack of autism knowledge & medical model view of ‘fixing’ autism
- Parents were most affected by grandparents’ judgements
- These judgements related to rigid social expectations
- Relatives were sometimes in denial or embarrassed about autism and wanted to blame others
- Parents highlighted wider societal exclusion, related to a lack of appropriate community facilities
- Contrastingly, parents reported a range of attributes associated with supportive attitudes

5. Implications

- The research provides important new knowledge about the lived experiences of parents of autistic children with learning difficulties, in relation to societal attitudes towards autism
- The research underlines the importance of education and support to change attitudes, particularly support services to help facilitate grandparents’ engagement and understanding of autism
- Parent insights about supportive attitudes contribute towards a positive model of societal attitudes towards autism

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