

# 'The educative journey of children with Down Syndrome, as experienced by their parents.'

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## 1. BACKGROUND

In addition to being those with a 'unique' knowledge of their child's needs (DfES, 2001, p.16, 2:2), parents of children with Down syndrome often have knowledge about effective educational provision for their children, which is 'frequently not matched by practitioners' in educational settings (APPGDS, 2012, p.6). The importance of the centrality of the views of the young person with special educational needs, and of their parents, is enshrined in legislation (Children and Families Act, 2014) and statutory policy (DfE & DoH, 2015) in England. Research reflects that parents of children with Down syndrome have a vital role in ensuring the best provision for their children (Lyons, Brennan & Carroll, 2016; Ricci & Osipova, 2012; Mullan, Prendeville & Kinsella, 2018). However, it also highlights a discrepancy between the knowledge level of some professionals in educational settings, including teachers, and the knowledge of parents and inconsistent practice across Local Authorities (Van Bysterveldt, A., Westerveld, M and Garvis, S., 2018; Kendall, 2019; Ricci & Osipova, 2012; House of Commons, 2019). Parents therefore have a key role as advocates for appropriate provision for their children and young people (Faragher, Robertson & Bird, 2020).

## 2. RESEARCH AIM

**To gain insights from the parents' perspectives of the educational journeys of their children, in order to inform a more consistently successful educational experience for learners with Down syndrome.**

## 3. RESEARCH QUESTIONS

- **What do the educational journeys of learners with Down syndrome have to teach us as education professionals?**
- **What insights do the parental perspectives offer into what contributes to a positive experience of education for these young people?**

## 4. THEORETICAL BASIS AND CONCEPTUAL FRAMEWORK



I just think, 'Just listen to what I'm saying'.

So I just think just listen to parents

The two concepts of *funds of knowledge* and *local understanding* informed a developing conceptual framework through which to understand the parental accounts of the educative experiences of their children. Funds of knowledge (González, Moll & Amanti, 2005) is founded on **the premise that home literacy experiences can be drawn upon to enhance provision**. Local understanding holds to a **belief in 'the literate potential of all children, with or without disabilities'** (Kliewer, 2008, pp. 9 & 10). Both concepts therefore presume competence. In addition to the importance of staff training, belief that 'all have the capacity to learn' is paramount (Faragher et al., 2020, p.6). The role played by attitudes, values and beliefs is highlighted elsewhere in the literature (Zoniou-Sideri & Vlachou, 2006).

## 5. PILOT STUDY

### METHODOLOGY

- Narrative approach
- Principles of life-history research that are about listening to 'the people it claims to serve' (Goodson & Sikes, 2001, p.8)

### METHOD

- Unstructured interviews
- Themes came from the data.
- Pre-conceived ideas could be challenged.

### PARTICIPANTS

3 parents of children/young people with Down syndrome (aged 7, 12 and 19). Different areas of the UK. Interviews were conducted remotely due to COVID -19.

### DATA ANALYSIS

Transcripts were analysed following Braun and Clarke's six-phase model of thematic analysis (Braun & Clarke, 2012). Analysis within this study takes an inductive approach which aligns with the interpretive nature of my research.

### RESULTS

**Theme 1: Parents (of children with Down syndrome) recognise the need for proactivity to ensure a positive educative experience.**

**Theme 2: Parental choice of setting related first to setting ethos; impact on wellbeing and social needs, then to learning.**

**Theme 3: Staff attitude and parent partnership are key in defining setting ethos.**

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I just needed to know that ... they cared really

It was just she cared really, the lady, she cared. She cared about Poppy.

## 6. CONCLUSIONS

Participant responses and previous research reflect the complexity of factors which impact upon the educational journey of children with Down syndrome. Whilst upholding the thesis that parents often have knowledge and experience, which can be drawn upon to inform a positive educational experience for children with Down syndrome, literature and early findings highlight the importance of:

- underlying beliefs about capability, inclusion and disability;
- attitudes to parental knowledge and
- underlying values upon which decisions are made.

Assumptions cannot be made about the outcomes of the main study based on the pilot study, but findings suggest that fundamental to achieving sustainable change, in terms of widespread positive educative experiences for young people with Down syndrome, is to challenge underlying beliefs, attitudes and values.

### KEY REFERENCES

(Additional references on accompanying PowerPoint)

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