

British Minority Parents with Children with Down Syndrome

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BACKGROUND

Little research focuses on the experiences and circumstances of British minority parents with children with disabilities. Chamba, Ahmad, Hirst, Lawton, & Beresford (1999) surveyed 600 British ethnic families with children with severe disabilities, which appears to be the largest study specific to British minority parents with children with disabilities to date in England. Some of the key findings included that families had challenges with obtaining sufficient finances and housing, and many experienced a lack of access to culturally appropriate services or services in general. Few qualitative studies about the experiences of British minority parents with children with disabilities exist (for example, see Croot, Grant, Mathers, & Cooper, 2012; Fazil, Bywaters, Ali, Wallace, & Singh, 2010; Rizvi, 2015), and there are even fewer about the experiences of British minority parents with children with Down Syndrome regardless of methodology (for example, see Cunningham, 1999; Sullivan, 2002). Therefore, this study helps to fill a gap in the research.

OBJECTIVES

A major aim of the study is to provide recommendations to improve services for minority families in the region and share insights from minority parents.

METHODOLOGY

Participants

Twenty-three British minority parents with children with Down Syndrome in the West Yorkshire area agreed to participate in this study that a local University Research Ethics Panel approved. Through in-depth interviews, parents were asked to share their reactions to their children's diagnosis and their experiences with seeking, accessing, and receiving services for their children. Experiences of coping strategies were also explored. Parents were asked about any experiences they or their children had with being stigmatized due to their religion and/or ethnicity. Not all parents identified their religious affiliation; however, more than half (65%) of the parents identified as Muslim. Some parents identified as Sikh and others Christian. In terms of heritage, parents identified as British Pakistani, British Indian, from Asian countries, from an Arab country, and Eastern Europe (and the spouse from another ethnic culture). Parents' ages ranged from 20 to 53 years old. Most 17 (74%) of their children were ages 2 to 11 years old, with 6 (26%) who were 12 years or older.

Research Question

The main research question of this qualitative study was "what are the experiences, challenges, and coping strategies of British Minority parents with children with disabilities?"

Data Analysis

Individual interviews were tape-recorded and transcribed verbatim except for one parent who preferred not to be recorded, and instead, detailed

handwritten notes were taken. Parents were interviewed in person or over the telephone according to their preferences. Qualitative software QDA Miner 5.034 was used for the analysis. The author and a research assistant undertook interrater reliability during the coding process. Due to this study's descriptive nature, qualitative content and thematic analysis were utilized to examine the interviews. Although this was a qualitative study, magnitude coding (Saldana, 2009) was used in some instances to quantify the number of parents who had similar experiences.

RESULTS

Key themes that emerged included: Advice to Improve Services; Advice to Other Parents; Experiences of Community Discrimination; and the Positive Impact of Charity Organizations/Support Groups.

Advice to Improve Services

Findings included that parents encountered both positive and negative experiences with various types of service providers. A key theme included the advice parents gave to improve services. This advice emerged due to challenges or barriers with services that parents faced or, in some cases, barriers that they had seen other parents face. A critical issue mentioned by many of the participants was the need for the training of professionals. Parents stated that some medical, school, and/or other professionals were not always appropriate in their communication with parents and/or were not competent in working with children with special needs. Many parents recommended training for professionals across various domains, including improving their communication skills, treating parents like "human beings," and increasing skills in working with children with special needs. Some parents reported inappropriate communication and incompetent behavior by professionals to their line managers.

Parents faced barriers and recommended improvements in time delays, long waiting lists, confusion over benefits, and service providers who do not know where to refer them. Parents recommended filling staffing shortages because children and families experienced gaps in services due to empty posts (including support teachers and Asian Family Support workers). Many parents mentioned language barriers for other parents as a critical problem, and they highly recommended a remedy for this gap.

Advice to Other Parents

Another central theme that was analyzed was the advice parents gave to other parents and families. The top pieces of advice that parents provided were to "educate yourself", seek out resources and services, and network with other parents and professionals. Many parents recommended attending local charity organizations/support groups that provide services for parents with children with Down Syndrome. One of the parents acknowledged it might be difficult for some parents to reach out and ask for help and services since it is not a cultural norm. Another parent advised, "Be proactive, ask questions about services.... even fight and be very persistent if needed...follow up and don't let things go." Some parents advised focusing on attributes such as being "strong," "grateful," "calm," and "turn to God, if you are a believer", and "stop worrying and live in the present."

Coping Strategies

Parents utilized various coping strategies, with faith being a key approach for many parents. Sixteen parents out of 23 (69.5 %) discussed their faith, and most related, their faith helped them cope. Many of the parents were Muslim or Sikh. At least one Christian spoke about their faith. Parents said they prayed or turned to God, and one parent said she taught her child to pray. Some felt that God had blessed them with their child, and they showed gratitude to God. One parent mentioned that she relied on the Surahs (in the Quran) to help calm her. A couple of parents questioned God due to their circumstances, but one learned to trust God after she questioned. A couple of parents relied on their friend's or husband's faith to help them in the early stages of parenting. Other coping strategies parents mentioned included the following, but to a lesser extent "keeping a positive mindset", self-care strategies, counseling, and advocating for their child. One of the lone parents reported that it was challenging to cope without a spouse and support system.

Experiences of Community Discrimination

Parents were asked if they faced any discrimination in the community due to their minority status. Four (17.3%) parents reported that they faced direct discrimination due to their religion/ethnicity, including physical, verbal, or other types of abuse, and even property damage. Eight (34.7%) parents reported what was interpreted as indirect discrimination, nine (39.2%) parents reported they experienced no discrimination, and two (8.8%) parents were not asked due to their time constraints. Some of the parents who said they experienced no discrimination noted that they were not Muslim but assumed they would experience discrimination if they were Muslim. The direct discrimination was egregious and compounded with at least two forms: for example, property damage and verbal abuse. Some indirect discrimination examples included that participants had been spoken to or treated differently and/or were treated inappropriately. Parents were concerned about the community discrimination towards Muslims and Sikhs and were very cautious and limited going out in the community (certain times and places). They did not travel alone, and in some cases, they increased home security. Some parents said they had to teach their children how to respond at school if they experienced verbal or physical abuse.

The Positive Impact of Charity Organizations/Support Groups

Overall, parents had positive experiences with charity organizations' education and support services as compared to all other services (medical, school, health, etc.) Parents spoke most highly about the positive impact of charity organizations' support services for them and other families. These charity organizations and support groups provided training and helped parents navigate other systems. Also, the benefit of the groups was that the groups were 'by parents for parents.' One group even provided training for professionals on how to communicate with parents.

CONCLUSIONS

The parents in this study shared critical information to help improve services for children and their families. They also provided first-hand advice to other parents and shared their experiences as minorities with community discrimination. The study recommendations include that the important information parents shared based upon their lived experiences can help other parents and provide evidence to improve service design and delivery. Furthermore, these findings can inform service providers, government officials, and policymakers who can act upon the parents' recommendations and improve the circumstances for families with children with disabilities.

Future Research

It is recommended that future studies specifically explore the experiences of minority parents who are lone parenting because they may face additional challenges without the support and/or income of a spouse.

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