

The dots just don't join up

Understanding the support needs of families of children on the autism spectrum



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Introduction

Parenting a child on the autism spectrum can be a hugely rewarding experience. It can also be stressful with reported stress levels exceeding those among parents of typically developing children, or those with other developmental conditions.

The absence of effective support to mitigate the impact of this additional stress can have significant negative implications for parents' well-being and potentially lead to an increased sense of isolation. This in effect creates a cyclical process that potentially perpetuates higher perceived levels of stress and poorer well-being.

Aim

This study therefore examined parents' perspectives on the support that they receive and the barriers to accessing effective support in order to modify support systems to improve parental and family well-being.

Our study was unique in three ways:

- It was co-produced by school professionals and by autism researchers.
- It directly elicited families' views and perspectives of the services and supports they would like to receive – rather than those that professionals think parents should like to receive.
- The views and experiences represented an ethnically, culturally and socio-economically diverse group of families, whose views are rarely heard in autism research.

Method

Participants

Survey 139 (108 female) respondents, all with autistic children who ranged in age from 4 years 4 months to 18 years 8 months. Of the 106 families who answered the question on ethnicity, 30 reported to be of White background, 55 of Black background, 11 of Asian background, 5 of mixed background and 5 of another ethnic group.

Interview Seventeen parents (15 mothers, 2 fathers) subsequently took part in an interview (7 who reported 'feeling unsupported' in the survey). These parents had 18 children (2 girls) ranging from 5 years 6 months to 17 years 7 months. Most children were of Black background (n=11; White background: n=4; Asian background: n=2).

Procedure

Survey Parents completed a series of demographic questions, two questions about parents' general health and mental well-being, a 5-item parental self-efficacy scale and three questions about the support they received or would like to receive.

Interview We asked parents their perceptions of the specific abilities and needs of their child, their child's wellbeing and their own wellbeing (physical and emotional), their experiences of support received both at school and at home, and the types of support they have benefited from and/or feel that they would benefit from in the future. Interviews were analysed using thematic analysis.

Conclusions

"You always worry what's going to happen"

Supporting parents of autistic children with additional intellectual disabilities and limited spoken communication around the specific areas of expressive language, diet, sleep and self-care skills should be seen as priorities for service providers.

"The support seems to isolate people...you manage your life as a family, you don't manage it in these isolated pockets"

By adopting a shared, collective, relational approach - one that is "more human, caring and time rich" and takes the time to develop strong relationships with the family, understanding their specific needs - service providers will be better able to identify families' unique cultural, family (especially sibling) and community characteristics, ensuring that the support received is tailored to the context of their everyday lives, and thus has a more positive impact on family well-being.

"It's the interactive quality, that's what I sort of need, I don't really deal well with paper and things that come through the post"

Formal support services need to take a more holistic approach to support provision that looks beyond the categorisation of need and subsequent allocation of resources based solely on clinically-defined difficulties experienced by the child him/herself to the perceived stress experiences of families more broadly.

"The most stressful thing each parent goes through is the constant fighting, fighting, knocking away on the doors for support, support that is supposed to be there but you are not getting it"

Overall, the results suggested that existing support (particularly from formal support services) was not meeting parents' needs. Existing support often fragments families rather than brings them together. Parents felt disconnected from formal services, which they perceived to have little understanding of their child and family and their specific needs.

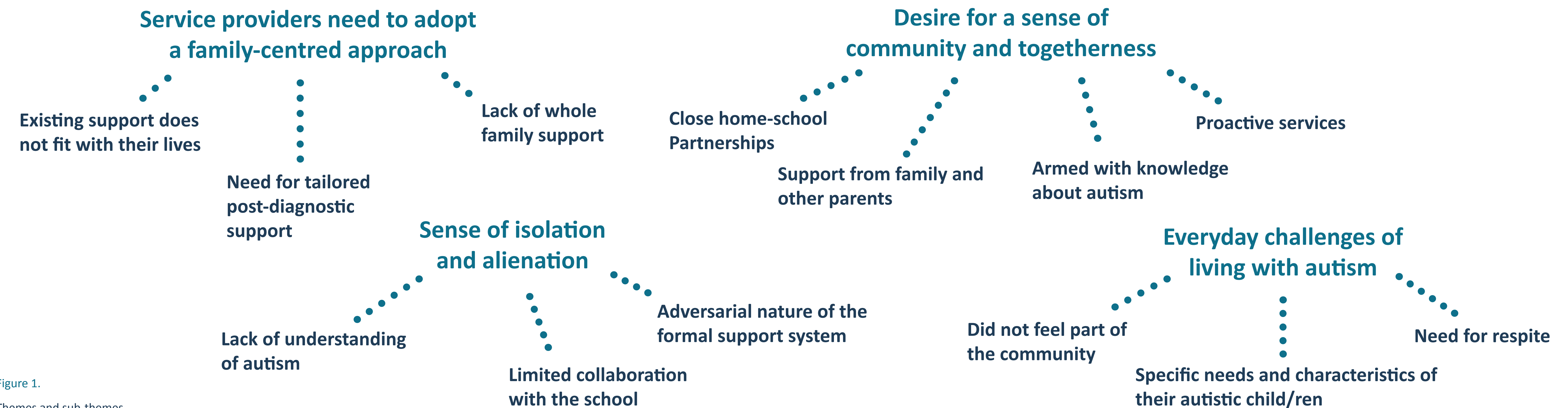


Figure 1. Themes and sub-themes identified in the interview data

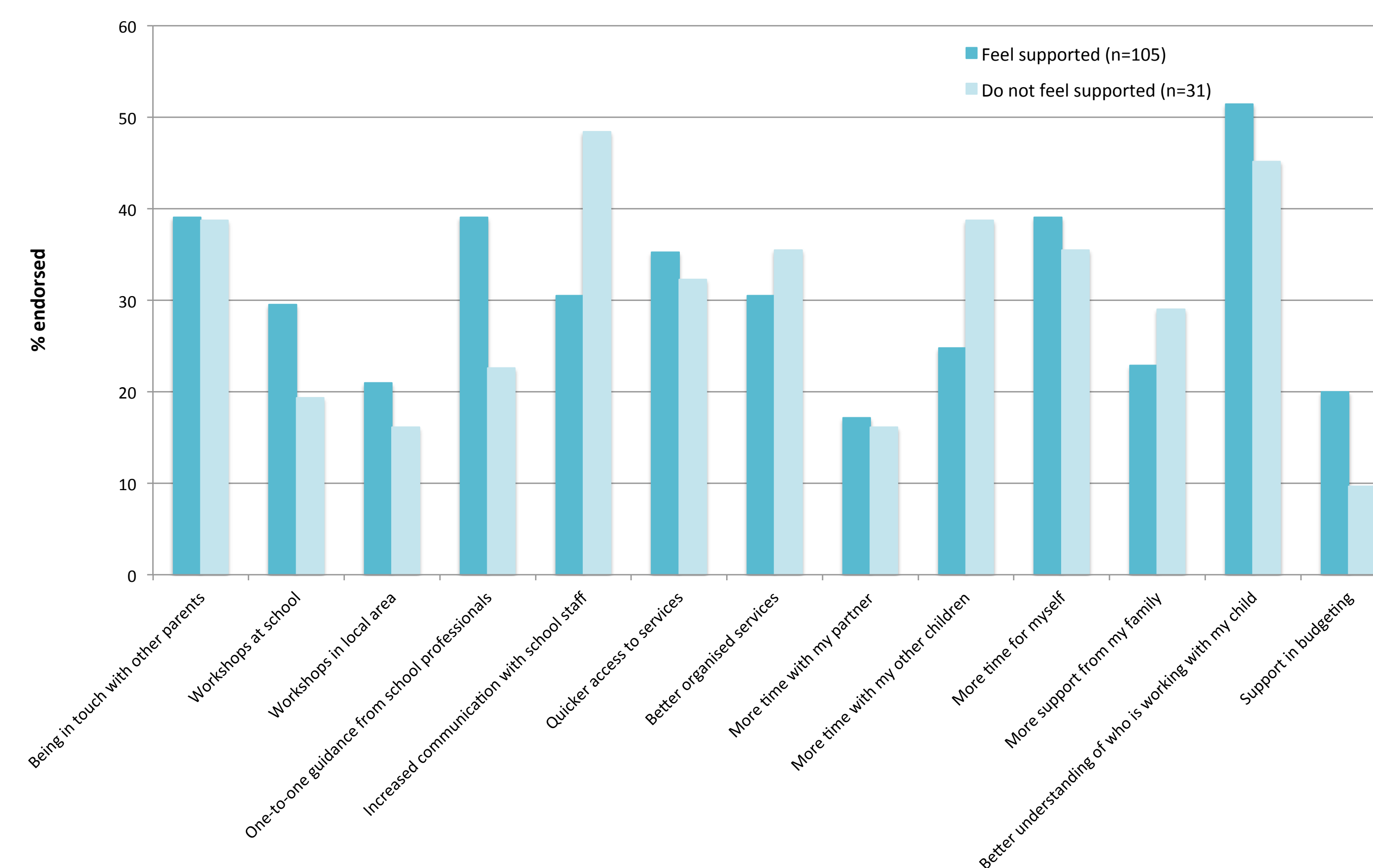


Figure 2. Graph showing the percentage of parents endorsing those supports they felt would make a difference to their or their child's lives according to whether they reported feeling supported or unsupported.

Results

Survey

Overall status of health and wellbeing

When rating their general health, the most common score (mode) was 'good'. 52% (n=72) rated their general health as 'very good' or 'excellent' while only 12% (n=16) rated their health as either 'fair' (n=13) or 'poor' (n=3). We found a similar pattern for ratings of mental/emotional health.

Parental self-efficacy

Parents' mean scores suggested that they generally perceive themselves as capable and effective in their parenting role.

Self-efficacy and health and wellbeing

Parents who reported lower degrees of perceived self-efficacy, also rated themselves as having significantly poorer health, and poorer mental or emotional health.

Support and self-efficacy and wellbeing

23% (n=31) of respondents reported that they did not have anyone to turn to for support. These parents did not differ significantly from those who reported they did have someone to turn to for support in terms of general health, mental health, or perceived parental self-efficacy.

Current Support

Parents reported receiving a wide variety of social supports but immediate family and friends were the most endorsed type of support. School and the family doctor were the most endorsed formal support.

Desired support

Parents endorsed a range of social and other support that would make the most difference to their or their child's lives (see Figure 2).

Interviews

Four main themes were identified (see Figure 1).