“Being an autism parent”
Mothers’ experiences from initial concerns about their daughters to a diagnosis of ASD: An IPA analysis

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INTRODUCTION
The ratio of males to females diagnosed with autism spectrum disorder (ASD) is approximately 4:1 (Fombonne, 2003). For Asperger’s syndrome, the ratio is 10:1 (Attwood, 2006).

It has been argued that this reflects a biological etiology where girls are generally protected but subject to greater impairment when affected (Baron-Cohen, et al., 2011). However, there is evidence that the discrepancy might also reflect different patterns of internalising and externalising behaviours in girls and boys and a focus on the male phenotype in diagnostic criteria and diagnostic tools derived from them (Van Wijngaarden-Cremers et al., 2014).

The dominance of a social construct of ASD based on males might contribute to the needs of cognitively able girls being identified at a later age (Rutherford et al., 2016) and the process of diagnosis sometimes taking longer (Beger et al., 2013). Both factors are associated with increased parental stress (Baird, Douglas, & Murphy, 2011) and there is some evidence that this might fall mainly on mothers (Vasilopoulou & Nisbet, 2016) perhaps due to traditional gender roles (O’Halloran, Sweeney, & Doody, 2013).

This thesis aimed to explore the diagnostic journeys of mothers of daughters in mainstream schools with diagnoses of ASD.

METHOD
Semi-structured interviews were conducted with five mothers with a daughter who met the following criteria:
- Had been given a diagnosis of ASD within the last five years
- Was of secondary school age
- Had mainly attended mainstream state schools
- Did not have other additional learning needs

Interviews lasted between 70 and 110 minutes. Transcripts were analysed using the six stages of interpretative phenomenological analysis (IPA) outlined by Smith, Flowers and Larkin (2009):
- Reading and re-reading of transcripts
- Initial noting of anything interesting or significant at descriptive, linguistic and conceptual levels
- Development of emergent themes from initial notes
- Searching for connections across emergent themes
- Moving to the next case
- Looking for patterns across cases

RESEARCH QUESTIONS
How do mothers of girls in mainstream schools experience the diagnostic journey of their daughters from initial concerns to a diagnosis of ASD?
How do mothers experience the outcomes of this diagnostic journey?

RESULTS
One participant said Asperger’s “had not created suffering” although she did describe difficulties in school; the other participants described very difficult journeys characterised by struggle and crisis.

The following superordinate and subordinate themes were identified in at least four of the five interviews. Illustrative quotations are shown for each subordinate theme. Theme titles are derived from quotations.

DIAMOND-SHAPED DAUGHTERS

Very Much a Swan
“She wears the most fantastic mask. You don’t know what’s going on underneath.”

So Uncomfortable
“She was in bits, the way she thought people thought of her, how she viewed herself.”

Going to Pieces
“A pain in the arse. I think they used to cringe if they see me coming.”

Who’s Got the Key?
“We saw three different GPs. We saw a nurse practitioner. And in the end I took her to A&E.”

Pain in the Arse
“A pain in the arse. I think they used to cringe if they see me coming.”

What the System Needs
“We only need her to be Level 4 and she’s already Level 6. What’s the problem?” (quoting school)

Rahled Over the Coals
“We had an awful time with the EWO.”

Breaking Point
“The OCD-type behaviours got worse and worse and it ruined everything in the end.”

THE STRESS CALLED ASPERGER’S

Surely That’s Boys
“I was naive enough to think it didn’t happen to girls.”

A Process of Discovery
“She’s got really really poor theory of mind. Really poor. It’s like wow!”

The Life I Wanted
“[I] couldn’t see how she would have the life that I wanted her to have.”

IMPLICATIONS FOR EDUCATIONAL PSYCHOLOGISTS
Sharing knowledge of the female phenotype: Understanding of ASD is dominated by our understanding of boys with ASD. EPs have a role in widening knowledge through training and, less formally, through day-to-day dialogue with school staff.

Promoting inclusion: Diagnosis alone does not improve lives. EPs have a role in helping schools to identify needs and to develop provision to meet those needs such as creating non-threatening formal spaces in school.

Enabling dialogue: Typically, schools did not refer daughters to EPs. Opportunities need to exist for EPs and SENCOs to discuss pupils who do not meet the threshold for formal referral.

LIMITATIONS
In keeping with the principles of IPA, these findings are ideographic and cannot be generalised (Smith et al., 2009); also, analysis remains subjective (Smith, 2004). Using five participants did not allow for a detailed analysis of the experiences of individuals and the nuances of each individual journey are lost in the overall analysis.

REFERENCES