



# Is the broad autism phenotype in mothers of children with autism spectrum disorder exacerbated by the challenges of caring for their children?

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## Abstract

**Study purpose:** This study raises the hypothesis that the additional demands of parenting a child with autism spectrum disorder (ASD) may lead to behavioural and personality changes consistent with the Broader Autism Phenotype (BAP).

**Background:** In a previous study, 16 mothers of children with ASD were interviewed about their quality of life. A number of mothers indicated that they believed the additional demands of parenting a child with ASD led to changes in their behaviour and personality. These changes are of particular interest in relation to the BAP, which refers to the presence of mild autistic traits in an individual. Researchers have typically used the existence of a BAP to indicate genetic liability for ASD. However, it is possible that behavioural and personality changes in response to parenting a child with ASD may be skewing scores on measures of the BAP, such as the Autism-Spectrum Quotient (AQ).

**Presentation of hypothesis:** This qualitative study of parental interviews provided a preliminary examination of whether behaviours consistent with the BAP may have been exacerbated by the challenges of raising a child with ASD.

**Testing methods:** Qualitative analyses from the previous study revealed that seven of the 16 mothers reported behavioural and personality changes since the onset of their child's ASD. We examine these behaviours in relation to the Autism-Spectrum Quotient and provided two potential designs for future studies to examine whether BAP-like behaviours may be exacerbated by parenting demands.

**Implications of the hypothesis:** A degree of caution is needed when researchers interpret measures of the BAP in parents who are full-time carers of their child with ASD. Some scores indicative of this phenotype may not solely represent a genetic liability for ASD. Longitudinal studies that explore the BAP among parents of children with ASD before, during and after the onset of caring will shed light on this complex research area.

**Keywords:** Autism, phenotype, mothers, autism spectrum disorders, genetic

## Introduction

Seventy years ago, the child psychiatrist, Leo Kanner, described mothers of children with autism spectrum disorder (ASD) as distant and aloof [1]. This concept of milder autistic traits in the relatives of children with ASD has developed considerably. Typically, researchers take these milder autistic traits to be the phenotypic expression of a genetic predisposition to ASD and have named them the *Broader Autism Phenotype* (BAP) [2].

Expressions of the BAP in relatives of people with ASD have been utilised as a complementary tool to explore the genetics of ASD [3]. The Autism-Spectrum Quotient (AQ) is one method of assessing the BAP. Respondents indicate on a scale how well each of 50 behavioural statements applies to them (strongly agree, agree, disagree, strongly disagree) [4]. Responses indicative of autistic-like traits are scored '1' (strongly agree/agree or strongly disagree/disagree) and others, '0'. Consistently, parents

of children with ASD score more highly than other parents [5].

However, the position that the BAP reflects a genetic liability for ASD ignores other influences on parental behaviour. Many challenges arise from rearing a child with ASD such as reduced sleep [6], more expenses [7], stigma [8] and managing violent or self-harming behaviours [9]. Currently, researchers have not considered that these challenges may influence parental BAP-like behaviours.

### Presentation of hypothesis

The first author interviewed 16 mothers of children with ASD [10]. There was no aim to examine the BAP but data relevant to this area emerged through our phenomenological analysis [11]. Seven of the mothers reported behavioural or personality changes since the onset of their child's ASD.

For example, when asked if her daughter's disability impacted on social relationships, one mother explained: 'My personality has changed too. I used to love fun and loved to get with people and have a great time'. Furthermore, she no longer enjoyed planning for the future and no longer bothered.

Another, when questioned about employment, detailed her enormous efforts of child-rearing and added that autism had put 'bad grooves in her personality'.

Attitudes towards social relationships were fundamentally altered following their child's diagnosis. Mothers were asked if they had ever felt included/excluded because of their child's disability?

In response, some spoke of the difficulty of retaining old friends and instigating new friendships. One mother expounded: 'You can't really go out with your friends anymore... You'd have to run after your child. You can't just sit down and say have a coffee...'

Another explained: 'You don't visit people. You don't have friends'. Two others spoke of their lack of time and energy to socialise. The first reported: 'I didn't have a social life... It takes effort to make friends. You have to reciprocate... There was nothing that I could do apart from care for my children'.

The other reflected: 'I've also lost interest in going out. I'm tired and so I just don't have the energy to do the sort of partying that I was involved with before... I became incredibly socially isolated because the moment I tried to have a conversation, my child would run away'.

In **Table 1**, several of these comments align with items mapping on to the 'Social Skill' subscale of the AQ.

Given the clear concordance between some mothers responses and items on the AQ, it is possible that BAP-like behaviours may increase after the onset of caring for a child with ASD. We hypothesize that BAP-like behaviours are not solely a genetic liability for ASD, but also a response to the challenges of parenting a child with ASD.

### Testing the hypothesis

Hypothesis testing is problematic since parents are not identifiable until after their child's diagnosis. A suitable longitudinal

**Table 1. Alignment of personality changes in mothers after a child's diagnosis with autism with items on the autism spectrum quotient.**

Autism spectrum quotient item	Mother's comment
1. I prefer to do things on my own rather than with others	I haven't had the time, the energy or the inclination to go and make friends
11. I find social situations easy (reverse scored)	I became incredibly socially isolated because the moment I tried to have a conversation my child would run away
22. I find it hard to make new friends	You can't really go out with your friends anymore... you'd have to run after your child. You can't just sit down and say have a coffee. You're always looking out the side there, wondering where she is
44. I enjoy social situations	I've also lost interest in going out

study could be a large-scale 'birth cohort' study, which administers the AQ to mothers at points throughout their child's life. We would predict a significant interaction between AQ scores of mothers of children with ASD and mothers of typically developing children when examined during their child's early (i.e., pre-diagnosis) and later (i.e., post-diagnosis) life. Given the infrequency of ASD occurrence, such a design might be prohibitively expensive. However there are already several large birth-cohort studies in existence (*Avon Longitudinal Study of Parents and Children* (ALSPAC) [12] and *Generation R* [13]) that could provide an opportunity for hypothesis testing. In a cross-sectional study, researchers could recruit two groups of parents: (a) full-time carers cohabiting with their child and (b) former carers, no longer cohabiting with their child. A between-groups comparison of AQ scores would provide useful data for hypothesis testing.

### Implications of the hypothesis

Our analyses did not identify similarities between mother responses and items pertaining to other scales on the AQ, such as Attention to Detail, Attention Switching and Communication and Imagination. However, we note that 'false-positives' on even one scale, can substantially influence interpretation of data. For example, mothers endorsing all items presented in **Table 1**, would score '4' for the 'Social Skills' subscale, which is a score indicative of the BAP in this subscale [5]. However, rather than solely reflecting a genetic liability for ASD, the nature and context of these mothers comments indicate that this score may also emphasize the difficulties with social relationships that accompany having a child with ASD.

Compare Kanner's description of mothers of children with ASD in his clinic to the following insight provided by a similar mother, 70 years later. She had made the decision to be very unemotional when talking to professionals about her son and

acknowledged the following coping mechanism.

'If I let myself get emotional with one of these people and with one of their questions, I thought the flood-gates are going to open and I'm never going to be able to get myself back from it'. In a similar way to Kanner, her husband reported 'You come across as very cold-hearted'.

These preliminary data urge caution when interpreting the scores of the AQ and other BAP assessments, particularly in the domains of social engagement and enjoyment. Behaviours consistent with the BAP may not solely represent a genetic liability for ASD, and scores on these assessments may be inflated by responses to having a child with disability.

### List of abbreviations

ASD: Autism Spectrum Disorder

BAP: Broader Autism Phenotype

AQ: Autism-Spectrum Quotient

ALSPAC: Avon Longitudinal Study of Parents and Children

### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

Authors' contributions	JF	CF	AJOW
Research concept and design	✓	✓	✓
Collection and/or assembly of data	✓	✓	✓
Data analysis and interpretation	✓	✓	✓
Writing the article	✓	--	✓
Critical revision of the article	✓	--	✓
Final approval of article	✓	✓	✓
Statistical analysis	✓	--	✓

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