

[Start](#)

[Browse by Day](#)

[Disclosure Index](#)

[Author Index](#)

[Meeting Information](#)

When:
May 11 - 14, 2016
Where:
Baltimore Convention
Center
Baltimore, MD

22276
Links Between Autism Spectrum Disorder Diagnostic Status and Family Quality of Life

Saturday, May 14, 2016: 11:30 AM-1:30 PM

Hall A (Baltimore Convention Center)

A. G. McKechnie^{1,2}, S. Fletcher-Watson³, V. Moffat⁴ and E. C. Johnstone⁵, (1)The Salvesen Mindroom Centre, The University of Edinburgh, Edinburgh, United Kingdom, (2)The Patrick Wild Centre, The University of Edinburgh, Edinburgh, United Kingdom, (3)University of Edinburgh, Edinburgh, Scotland, United Kingdom, (4)University of Edinburgh, Edinburgh, United Kingdom, (5)University of Edinburgh, Edinburgh, United Kingdom of Great Britain and Northern Ireland

Background: Quality of life is often lowered, relative to the norm, in families with children with additional needs. This may be particularly the case where additional needs are accompanied by an autism spectrum disorder (ASD). Rates of diagnosis in Scotland (where this study took place) are low relative to the UK average, and global prevalence estimates. Therefore it is likely that some cases of ASD remain undiagnosed in Scotland. It is unclear what the consequences of this may be.

Objectives: We explore the effects of autism diagnostic status, investigating impact on family well-being of: i) diagnostic status; ii) access to services; iii) ASD symptom intensity; iv) presence of challenging behaviours and v) IQ.

Methods: Mothers (n=76) of young people (aged 13-22 years) with educationally-defined additional needs completed standardised questionnaires about quality of life, stress, service provision, challenging behaviour (Child Behaviour Checklist, CBCL) and presence and severity of ASD traits (Social Communication Questionnaire, SCQ). Participants were a sub-group selected from a large national teacher-referral study (n=465). The sample was divided, based on case history and SCQ scores into three groups: a) additional needs, SCQ score below threshold; b) additional needs, SCQ score above threshold and ASD diagnosis; c) additional needs, SCQ score above threshold, no diagnosis. In addition, a group of mothers of typically developing young people (n=17) completed standardised questionnaires on quality of life and on the behaviour of their son or daughter.

Results: Quality of life was highest, and stress lowest, in mothers of TD young people. Among the three groups with additional needs, higher SCQ scores were related to poorer quality of life and higher stress. This relationship was not explained by levels of challenging behaviour or IQ and was apparent across groups with and without a pre-existing ASD diagnosis.

The lowest quality of life and highest stress scores were evident in the group of mothers of young people who did not have a diagnosis of ASD but did exceed threshold on the SCQ. The two high-SCQ groups (with and without ASD diagnosis) did not differ on access to service provision, mean SCQ score or mean CBCL score. However mothers of young people with high SCQ scores but without ASD diagnosis did rate services as less useful than other groups.

Conclusions: Mothers of young people with additional needs experience lower quality of life and higher stress than mothers of typically developing young people. These adverse effects are stronger in the presence of ASD diagnosis, and strongest when there are signs of ASD but no diagnosis. This pattern is not explained by young people without ASD diagnosis having: higher levels of challenging behaviour; less access to services; low IQ. The study demonstrates that presence of ASD-like symptoms in the absence of diagnosis may be a particular cause of stress and poor quality of life for families.

See more of: [Family Issues and Stakeholder Experiences](#)

See more of: [Family Issues and Stakeholder Experiences](#)