# WORKING WITH PARENTS AND CARERS OF AUTISTIC GIRLS

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### INTRODUCTION: WORKING WITH PARENTS AND CARERS OF AUTISTIC GIRLS

- Research carried out as part of the Doctorate in Education and Child Psychology at the University of Manchester
- How can Educational Psychologists work effectively with parents/carers of autistic girls?

#### **Note on Language**

- Autism-first terminology
- Binary language (autistic girls)



#### RATIONALE FOR THE RESEARCH

Existing autism literature is bias towards autistic males

Research has highlighted the under-identification, under-diagnosis, and late diagnosis of autism in girls (Duvekot et al., 2017).

Recently, literature has identified differences in the presentation of autism in females (Happé & Frith, 2020).

Gap in the literature of working with parents and carers of autistic girls

#### THE FEMALE PRESENTATION OF AUTISM

More internalised difficulties, such as anxiety (Gould & Ashton-Smith, 2011).

A stronger desire to fit in with peers (Lai et al., 2015).

Reduced repetitive externalising behaviours such as hand flapping (Gould & Ashton-Smith, 2011).

More 'random' restricted interests, which may appear in line with the interests of their neurotypical peers (Hiller et al., 2014).

Autistic girls tend to 'mask' their social challenges compared to autistic boys (Dean et al., 2017).

#### THE FEMALE PRESENTATION OF AUTISM: EXAMPLES

More obvious characteristics	More subtle characteristics
May not show eye contact or interest in social niceties	May have more of a desire to 'fit in' with peers and show more socially normative behaviour from copying others
Interests may be more technical, or object based such as cars or trains	May be passionate about animals, drawing or reading
Extremely repetitive and ritualistic behaviours such as hand flapping, jumping, lining up objects	May have a rich and elaborate fantasy and dream world.  May repetitively re-watch their favourite films or re-read their favourite books



### THE IMPACT OF MASKING

Masking has been discussed as a partial explanation of the missed and late diagnosis of autism in girls (Duvekot et al., 2017). There is emerging evidence that masking can have negative consequences for autistic girls:

Masking can be exhausting and distressing, which may impact on relationships, learning and mental health (Halsall et al., 2021).

Masking can result in physical and emotional exhaustion, and issues around identity and authenticity (Hull et al., 2020).

Greater masking demands within the school setting lead to social exhaustion at home (Anderson et al., 2020)-Suggests that autistic girls' needs tend to be more pronounced at home.

#### WORKING WITH PARENTS

Allows for a more holistic view of a child, behaviour in one context can have a significant effect on the other (Pellegrini, 2009).

Aligns with the SEND Code of Practice (2014).

Explored Educational Psychologists' perspectives of effective practice and areas of further development when joint working with parents/carers of autistic girls:

What is effective?

What is an area of further development?

#### **Effective practice:**

Listening to parent concerns

EP's having up to date knowledge of the female presentation of autism

Raising awareness of autistic girls

Working collaboratively with parents

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"...these autistic girls are trying so hard to kind of fit in and keep a lid on it and mask at school, then they come home, and they feel so comfortable at home with their...parents, they can show almost like the worst side of themselves, and they can let it all out because they know it's safe. So, **believing** the parents...that that is happening has been...really important..."

"we need to come from...a really calm place of understanding and having **empathy** for the parents about maybe the journey that they've been on"

#### **Effective practice:**

Listening to parent concerns

EP's having up to date knowledge of the female presentation of autism

Raising awareness of autistic girls

Working collaboratively with parents

"I do feel that we need to have an up-to-date understanding of autism and girls because it is, you know, a relatively new area in terms of research, compared to boys with autism..."

#### **Effective practice:**

Listening to parent concerns

EP's having up to date knowledge of the female presentation of autism

Raising awareness of autistic girls

Working collaboratively with parents

"I think it's trying to help parents understand where that's coming from...and what that behaviour is trying to communicate"

"helping staff within school to understand that it may be that those children are internalising"

#### **Effective practice:**

Listening to parent concerns

EP's having up to date knowledge of the female presentation of autism

Raising awareness of autistic girls

Working collaboratively with parents

"...I think it always helps to have it...quite led by...the parents in terms of...what are their concerns?"

#### **Areas for further development:**

Need for increased involvement with parents

More structured training for parents and school staff

Differing views of home and school

#### **Areas for further development:**

Need for increased involvement with parents

important voice to have in consultation"

"they [parents] do know their children better than anybody and so they are a really

More structured training for parents and school staff

"...that would be sort of like the gold standard...just being alongside them on that journey, helping them to...understand, you know, that process, the diagnostic process and what that means, what the implications of that are."

Differing views of home and school

#### **Areas for further development:**

Need for increased involvement with parents

"parent workshops to... upskill parents...in terms of knowledge and interventions, you know, useful strategies"

More structured training for parents and school staff

"[for school staff to] have those conversations with parents earlier on, I think, would be really, really helpful in terms of kind of getting better long-term outcomes"

Differing views of home and school

"that's something that I would definitely like to do...you know, training for staff in schools...that would be really good."

#### **Areas for further development:**

Need for increased involvement with parents

More structured training for parents and school staff

Differing views of home and school

"sometimes, I think...[parents] just feel that maybe school staff...or us don't necessarily really realise how...challenging the behaviours are at home..."

"I think sometimes parents don't feel like they're being believed, you know, when they're talking about what's going on at home, I think sometimes they feel like school staff don't believe them because they don't see it..."

"Those children...that are presenting with quite challenging behaviours are the ones who are going to get...the EP time and so I really do think there are so many girls there...who are just not even being picked up...they're just not even being identified..."

#### **NEXT STEPS:**



Research exploring parents' perspectives of what they would consider to be effective, and areas of further development, when working with EPs to support their autistic daughters.

#### REFLECTIONS AND DISCUSSION

- What aspect of this research are you most interested in?
- What areas would you like more resources in?

#### USEFUL LINKS AND RESOURCES

- National Autistic Society (NAS) <a href="https://www.autism.org.uk/">https://www.autism.org.uk/</a>
- Online training (autistic women and girls) <a href="https://www.autismonlinetraining.com/">https://www.autismonlinetraining.com/</a>
- Autistic girls network charity <a href="https://autisticgirlsnetwork.org/">https://autisticgirlsnetwork.org/</a>
- Short film to support professionals in identifying the different presentations of autism <u>https://autismwales.org/en/community-services/i-work-with-children-in-health-social-care/the-birthday-party/</u>
- Nasen guide to girls and autism <a href="https://nasen.org.uk/resources/girls-and-autism-flying-under-radar">https://nasen.org.uk/resources/girls-and-autism-flying-under-radar</a>
- Girls and Autism book Carpenter, B., Happé, F., & Egerton, J. (Eds.). (2019). Girls and autism: educational, family and personal perspectives. Routledge.

#### REFERENCES

- Anderson, J. Marley, C., Gillespie-Smith, K., Carter, L., & MacMahon, K. (2020). When the mask comes off: Mothers' experiences of parenting a daughter with autism spectrum condition. Autism, 24(6), 1546-1556.
- Botha, M. (2021). Critical realism, community psychology, and the curious case of autism: a philosophy and practice of science with social justice in mind. Journal of Community Psychology.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.
- Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: strengthening its practice. Annu. Rev. Public Health, 29, 325-350.
- Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender difference in the social behaviors of girls and boys with autism spectrum disorder. Autism, 21(6), 678-689.
- Department for Education and Department of Health (2015). Special Educational Needs and Disability Code of Practice: 0 to 25 Years.
   London: Department for Education, & Department of Health.
- Duvekot, J., van der Ende, J., Verhulst, F. C., Slappendel, G., van Daalen, E., Mara, A. & Greaves-Lord, K. (2017). Factors influencing the probability of a diagnosis of autism spectrum disorder in girls versus boys. Autism, 21(6), 645-658.
- Fallon, K., Woods, K., & Rooney, S. (2010). A discussion of the developing role of educational psychologists within Children's Services. Educational Psychology in Practice, 26(1), 1-23.
- Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. Good Autism Practice (GAP), 12(1), 34-41.
- Halsall, J., Clarke, C., & Crane, L. (2021). "Camouflaging" by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators. Autism, 25(7), 2074-2086.

#### REFERENCES

- Happé, F. & Frith, U. (2020). Annual Research Review: Looking back to look forward changes in the concept of autism and implications for future research. Journal of Child Psychology and Psychiatry, 6 I (3), 218-232.
- Hiller, R. M., Young, R. L., & Weber, N. (2014). Sex differences in autism spectrum disorder based on DSM-5 criteria: evidence from clinician and teacher reporting. *Journal of abnormal child psychology*, 42(8), 1381-1393.
- Hull, L., Petrides, K.V. & Mandy, W. The Female Autism Phenotype and Camouflaging: a Narrative Review. Rev J Autism Dev Disord 7, 306–317 (2020).
- Lai, M.-C., Lombardo, M.V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: setting the scene for future research. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(1), 11-24.
- MacKay, T. (2006). The educational psychologist as community psychologist: Holistic child psychology across home, school and community. Educational and Child Psychology: Community Psychology: Theoretical and Practical Implications for Educational Psychologists, 23(1), 7–15.
- Pellegrini, D.W. (2009). Applied systemic theory and educational psychology: Can the twain ever meet?. Educational Psychology in Practice, 25(3), 271-286.
- Ratto, A. B., Kenworthy, L., Yerys, B. E., Bascom, J., Wieckowski, A. T., White, S. W., Wallace, G. L., Pugliese, C., Schultz, R. T., Ollendick, T. H., Scarpa, A., Seese, S., Register-Brown, K., Martin, A., & Anthony, L. G. (2018). What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills. Journal of autism and developmental disorders, 48(5), 1698–1711.
- Taylor, Simon Peter (2018) Critical realism vs social constructionism & social constructivism: application to a social housing research study. International Journal of Sciences: Basic and Applied Research, 37 (2). pp. 216-222
- Vincent, S., & O'Mahoney, J. (2018). Critical realism and qualitative research: An introductory overview. The sage handbook of qualitative business and management research methods.

## THANK YOU FOR LISTENING

ANY QUESTIONS?

