#### <u>Social camouflaging in autism – is it time to lose the mask?</u>

Will Mandy

Many autistic people feel obliged to pretend not to be autistic. They invest considerable effort daily in monitoring and modifying their behaviour to conform to conventions of non-autistic social behaviour. This phenomenon has come to be called 'social camouflaging', also referred to as 'masking', 'compensation' and 'pretending to be normal' (Lai et al., 2017; Hull et al., 2017; Livingston et al., 2019). Camouflaging strategies are diverse. Some are relatively simple, for example, when someone takes the decision not to do their favourite stims when amongst non-autistic people, or develops rules to use eye contact in a conventional manner. Other camouflaging strategies are elaborate and complex, developed via a careful, conscious and often protracted campaign of learning. An example would be a teenage autistic girl purposefully studying the behaviour of a non-autistic girl at school, and then, over time, adopting her attitudes, dress, gestures, and facial expressions, thus developing a persona to navigate social situations.

Social camouflaging is widespread amongst autistic people. In one recent online study, 70% of autistic adult participants reported that they consistently camouflage (Cage & Troxell-Whitman, 2019). Despite how common camouflaging is, until recently autism researchers overlooked it. Of course, autistic people have long known about camouflaging. It features prominently in autistic life writing, notably in Liane Holliday-Willey's best-selling memoir 'Pretending to Be Normal' (1999). Also, a small number of clinicians have, over the last few decades, shown an awareness of social camouflaging. Lorna Wing (1981), the eminent British psychiatrist and pioneer of autism practice, when considering the under diagnosis of autistic girls, put forward the idea of camouflaging; and several clinicians have subsequently

written insightfully about this aspect of autistic experience, based on their work with autistic children and adults (e.g., Atwood, 2006; Gould, 2017). But researchers can be slow to catch on, and it is only in the last five years that we have seen the publication of rigorous studies that yield science-based insights into autistic camouflaging. In this editorial I summarise some of the insights that have come from this small but burgeoning literature. The emerging findings offer important perspectives into what is, in my view, the most important question in autism research, namely, 'how best can autistic people be helped to lead more satisfying, productive and enjoyable lives?'

## Reasons for camouflaging

Why do autistic people camouflage? When we asked this question of one autistic woman, she replied "I want to avoid the bullying mostly" (Hull et al., 2017). This is a typical response across studies (e.g., Tierney et al., 2016; Livingston et al., 2019). For many autistic people camouflaging is experienced as an obligation, rather than a choice. It is often motivated by a sense of alienation and threat, and frequently represents an attempt to avoid ostracism and attacks. Such findings offer a vivid reminder of the daily challenges autistic people face: they show us the pervasive difficulties of being autistic in a world that is shaped by the non-autistic majority. When an autistic person camouflages, in many cases it is an attempt to manage the mismatch between their natural way of being and the demands their social environment places on them. Everyone faces conflicts between authenticity and pragmatism, but for autistic people this is often especially stark.

# Consequences of camouflaging

Autistic people describe some benefits of camouflaging (e.g., Hull et al., 2017). It can enable its practitioners to achieve goals, such as getting an education and holding down a job. It can also help establish relationships, in particular with non-autistic people.

Despite the advantages of camouflaging, my reading of the literature is that, for most people, these benefits are outweighed by costs. Camouflaging can hide an individual's difficulties, preventing them from being understood and helped. Unsurprisingly, camouflaging can delay or even prevent diagnosis –an individual who has become expert at pretending not to be autistic is less likely to be referred for an autism assessment, and less likely to be diagnosed if they are assessed (Bargiela et al., 2016). This appears to play an important role in the diagnostic biases against autistic girls and women, who are more likely than boys and men to use camouflaging strategies (Hull et al., 2019).

Social camouflaging is associated with mental health challenges. In qualitative research, autistic people consistently link their camouflaging to experiences of anxiety and depression (e.g., Bargiela et al., 2016). Several quantitative studies show associations between camouflaging and internalising problems: autistic people who camouflage also tend to report higher rates of anxiety and depression (e.g., Cage & Troxell-Whitman, 2018; Livingston et al., 2019). One study found that self-reported camouflaging is associated with higher rates of suicidality (Cassidy et al., 2018).

It is not clear whether the association between camouflaging and mental health problems reflects an underlying causal relationship: does camouflaging drive the development of mental health problems? Studies addressing this question will involve testing putative mechanisms whereby camouflaging could lead to poor mental health. The qualitative literature already suggests some hypotheses. Camouflaging is commonly reported to be exhausting and stressful, potentially leading to autistic burnout (e.g., Tierney, Burns & Kilbey, 2016; Livingston et al., 2019). Furthermore, the habitual practice of pretending not to be autistic can erode a person's sense of identity (e.g., Hull et al., 2017), and can lead to their needs being misunderstood or overlooked entirely (Bargiela et al., 2016). In addition, Cage and colleagues (2018) have suggested that camouflaging may mediate the relationship between social stressors (e.g., bullying, lack of autism acceptance) and subsequent anxiety and depression. Another possibility is that the association between camouflaging and mental health represents the effect of an unmeasured third variable, for example, being in an environment that is inhospitable to autistic people. It will be valuable to investigate empirically the mechanisms that potentially link camouflaging and mental health difficulties. Such work will not only yield insights into the effects of camouflaging, but can contribute answers to the wider question of why autistic people are at such high risk of suffering poor mental health.

#### Wider lessons from camouflaging research

I have argued that camouflaging represents one way in which autistic people manage the challenges they face whilst operating in social environments that are mainly shaped by non-autistic people. In one sense camouflaging is adaptive. It is a creative, resourceful response to difficulties (Lai & Szatmari, 2019). But the evidence to date suggests that it is associated with exhaustion, stress, anxiety, depression, identity confusion and even suicidality. Thus, it would appear that the attempts that autistic people make to adapt to the non-autistic social world can be deleterious to wellbeing.

The study of camouflaging highlights a wider point about the role of the environment in the development of the difficulties that many autistic people face. Too often, the problems of autistic people have been assumed to arise simply from their own individual deficits. Camouflaging research reminds us that this is wrong: the problems autistic people face arise from a misfit between the individual's unique pattern of strengths and difficulties, and the demands their environment places on them. For example, if an autistic boy refuses to go to school, this is a problem – but it is not a problem inherent to the child. Rather it arises from an interaction between that child and the environment in which he operates. In this case it may be that the school places social and cognitive demands upon the child that exceed his capacities; and does not make enough use of his strengths.

If we view the difficulties of autistic people using this more ecological, context-based approach, we can derive the principle that autism intervention should aim to improve the fit between the individual and their environment. Camouflaging research shows us that attempts to do this only by changing the individual, without modifying the environment, run the risk of being ineffective or, even worse, harmful. Unfortunately, to date, much of the evidence base for autism interventions focuses on interventions that place the onus on autistic individuals to change (Wong et al., 2015). These include a range of treatments that, in various ways, seek to make autistic people act or think differently. In developing the evidence base for supporting autistic people, we need to place greater emphasis on interventions that improve the person-environment fit by modifying the environment, rather than the person (e.g., Mandy et al., 2016).

Currently there is a lively social media conversation about camouflaging taking place amongst some autistic people, centred on the hashtag #TakeTheMaskOff. In this conversation, autistic people commonly state that they would like to be able to camouflage less. But it is also acknowledged that this can be difficult, as people fear the consequences of being more openly autistic, for example, at work or in social settings. An active campaign is needed to shape public attitudes and understanding, to increase autism acceptance and tolerance. This can help create more community, educational, and work spaces where autistic people are freer to be themselves; and have a better chance of actualising their talents. A measure of success in this venture will be if an increasing number of autistic people feel able to camouflage less.

### Acknowledgements

I would like to thank David Mandell, Meng-Chuan Lai, Laura Hull and Julia Cook, all of whom helped improve this editorial by giving feedback on an earlier draft.

#### REFERENCES

Atwood, T. (2006). Asperger's and Girls. Future Horizons: Arlington, Tx

- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of autism and developmental disorders*, *49*(5), 1899-1911.
- Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, 48(2), 473-484.
- Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular autism*, 9(1), 42.
- Gould, J. (2017). Towards understanding the under-recognition of girls and women on the autism spectrum. *Autism*, 21(6), 703-705.
- Holliday-Willey, L. (1999). Pretending to Be Normal. JKP: London.
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519-2534.

- Hull, L., Lai, M. C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K. V., & Mandy, W. (2019). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism*, 1362361319864804.
- Lai, M. C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., ... & MRC AIMS Consortium. (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism*, 21(6), 690-702.
- Lai, M. C., & Szatmari, P. (2019). Resilience in autism: Research and practice prospects.
- Livingston, L. A., Colvert, E., Social Relationships Study Team, Bolton, P., & Happé, F. (2019). Good social skills despite poor theory of mind: exploring compensation in autism spectrum disorder. *Journal of Child Psychology and Psychiatry*, 60(1), 102-110.
- Livingston, L. A., Shah, P., & Happé, F. (2019). Compensatory strategies below the behavioural surface in autism: a qualitative study. *The Lancet Psychiatry*, 6(9), 766-777.
- Mandy, W., Murin, M., Baykaner, O., Staunton, S., Cobb, R., Hellriegel, J., ... & Skuse, D. (2016). Easing the transition to secondary education for children with autism spectrum disorder: An evaluation of the Systemic Transition in Education Programme for Autism Spectrum Disorder (STEP-ASD). *Autism*, 20(5), 580-590.
- Tierney, S., Burns, J., & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the autistic spec- trum. *Research in Autism Spectrum Disorders*, 23, 73–83.
- Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., ... & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of autism and developmental disorders*, 45(7), 1951-1966.
- Wing L (1981) Sex ratios in early childhood autism and related conditions. *Psychiatry Research* 5(2): 129–137.